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Tempering hope with Intimate Knowledge: Contrasting emergences of the concept 'uninfectious' in HIV

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Abstract

In this paper, we contrast two emergences of the concept of 'uninfectious' (that pharmaceuticals can render someone living with HIV non-infectious) in HIV. First, using Novas' framing of 'political economies of hope', we describe the deployment of 'uninfectious' as part of global health campaigns. Second, we draw on Raffles' (*International Social Science Journal*, 2002, 54, 325) concept of 'intimate knowledge' to theorise our own account of 'uninfectious' through a re-analysis of qualitative data comprising the intimate experiences of people living with or around HIV collected at various points over the last 25 years. Framed as intimate knowledge, 'uninfectious' becomes known through people's multiple engagements with and developing understandings of HIV over a prolonged period. As contingent and specific, intimate knowledge does not register within the biomedical/scientific ontological system that underpins discourses of hope employed in global campaigns. The concept of intimate knowledge offers the potential to critique discourses of hope in biomedicine problematising claims to universality whilst enriching biomedical understandings with accounts of affective, embodied experience. Intimate knowledge may also provide a bridge between different epistemological traditions in the sociology of health and illness.

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KEYWORDS

(Bio) medicalisation, embodiment, HIV/AIDS, intimacy, secondary analysis (qualitative), sociology of scientific knowledge

BACKGROUND

Over four decades, an immense corpus of knowledge on psychosocial, socio-economic, cultural and political aspects of HIV has been generated. However, the success of pharmaceutical treatments in combatting HIV over the last 25 years has facilitated the ascendance of distinctively biomedical forms of knowledge which now dominate contemporary understandings (the 'biomedical era'). This ascendance can be traced through a series of moments commencing with the development of highly effective anti-retroviral treatments in 1996; each subsequent moment marking an innovation, a re-deployment or an expansion of the claims made for pharmaceutical treatments. Thus, treatments were re-deployed in protocols to prevent vertical transmission from 2000, as a post-exposure prophylactic treatment (PEP) to prevent transmission following sexual exposure from 2005 and as a quotidian regimen to prevent sexual transmission (pre-exposure prophylaxes or PrEP) in the 2010s.

In the same period, scientific consensus emerged that, when used optimally, pharmaceutical treatments render those infected with HIV non-infectious to sexual partners. Similar moments mark the emergence of 'uninfectious' as a biomedical, epidemiological and social 'reality' including an announcement from the Swiss Federal Commission for AIDS/HIV, outlining conditions under which an HIV-positive person could be considered functionally non-infectious (Vernazza et al., 2008), and the results of a series of clinical trials (the HPTN 052 trial, the PARTNER and Opposites Attract studies) confirming that in repeated trials, no HIV transmissions occurred among HIV serodifferent couples when the partner with HIV has a consistently suppressed viral load (Bavinton et al., 2018; Cohen et al., 2011; Rodger et al., 2019).

At present, the HIV landscape is dominated by two global policy initiatives both of which deploy the concept 'uninfectious'. The first is the 'U = U (Undetectable = Uninfectious)' global consensus statement that people with HIV who have an undetectable viral load are uninfectious. The second is the UNAIDS Fast-Track Initiative to end AIDS by 2030 which commits states to drastically reduce the annual number of new infections globally by 2030 through rendering the majority of people with HIV uninfectious through uptake of HIV treatments (UNAIDS, 2014).

Many social scientists are sceptical of the hyperbole surrounding these campaigns, claims and targets (Kippax & Stephenson, 2016). These reservations stem from an awareness of geo-political factors leading to uneven treatment access and considerable research showing that the embodied experience of, and collective responses to, biomedical developments are complex, protracted and stratified by social and other forms of capital (Davis, 2010; Fassin, 2007; Keogh & Dodds, 2015; Kippax & Stephenson, 2016; Mykhalovskiy et al., 2004; Nguyen, 2010; Paparini & Rhodes, 2016; Persson et al., 2016; Squire, 2013; Young et al., 2019). This scepticism bespeaks long-standing ontological disconnects between the ways in which concepts such as 'uninfectious' are constructed within the realm of biomedicine and how they are experienced in people's lives.

In this paper, we contrast two emergences of the concept 'uninfectious' with regard to HIV. First, we consider its deployment within what Carlos Novas has described as a 'political economy of hope' (Novas, 2006). We then draw on Hugh Raffles' concept of 'intimate knowledge' (Raffles, 2002) to theorise our own account of the development and deployment of understandings of 'uninfectious' in the embodied and intimate experiences of people living with or around HIV. Thus, we consider divergences between public pronouncements designed to shape public and professional perceptions, and the emergence of private embodied understandings of uninfectiousness.

This paper makes a twofold contribution: In the context of HIV prevention, it provides alternative accounts of the production and deployment of knowledge about ‘uninfectious’; accounts which trouble dominant contemporary framings of this concept as a scientific or epidemiological breakthrough on one hand and/or a communitarian/political call to action on the other. In the context of the sociology of health and illness, this paper proposes *Intimate Knowledge* as an epistemological bridge between deployments of scientific knowledge within political economies of hope on the one hand and affective knowledge developed through experiences of health and illness on the other. By considering how these two knowledge forms interact, we hope to enable the generation of less partial accounts of biomedical transformations.

Political economies of hope

By locating patient activism within the sphere of biopolitics, Novas (Novas, 2006) draws out its intrinsically political character, for which HIV is arguably the template (Epstein, 1996). Considering political economies of hope entails broadening our analysis from one where hope is seen as an act of imagination or defiance on the part of those living with a disease to hope being materialised through collective social enactments (Herbrand & Dimond, 2018; Petersen & Wilkinson, 2015). Thus, patient activism shapes and is shaped by biomedical research agendas and realises specific forms of bio-political capital through enactments in spaces beyond the clinic: at conferences and meetings, in news and social media. Recent critical analyses of hope discourses in health and biomedicine have identified roles of ‘activists’ involved in actuating and mobilising specific forms of capital (Novas, 2006) and ‘witness/advocates’ who strategically narrativise their experiences as political tools, and ‘beneficiaries’ exhorted to engage with the technology (Herbrand & Dimond, 2018).

This characterisation of hope entails a commitment to mobilising these different forms of capital to bring certain futures into being (Bernays et al., 2007; Brown & Michael, 2003; Brown et al., 2000) with an expectation that current investment—in research, in education, in establishing personal and community health norms—will reap dramatic benefits in terms of lives saved, infections avoided etc. Thus, hope serves to align the aims and actions of diverse groups—patients, researchers, clinicians etc.—with the actualisation of a specific future and it is these characteristics of strategising, collective alignment and future orientation that makes an analysis of hope within a political economy framework possible and useful (Novas, 2006).

Each of the biomedical ‘breakthrough moments’ that make up the ‘HIV biomedical era’ (the development of effective anti-retroviral therapies, their redeployment as Post- and Pre-Exposure Prophylaxes for sexual exposure (PEP and PrEP), the Swiss Statement, the HPTN 052 trial, PARTNER and Opposites Attract study results) provides a fulcrum for activities by patient and community groups, civil society organisations, governments and global agencies aligning these activities ever more closely with highly ambitious, hopeful, affect-laden futures such as ending HIV by 2030. Thus, the deployment of ‘uninfectious’ in the U = U and Fast-Track initiatives mobilises hybrid technologies of hope (Michael & Rosengarten, 2013) dependent on forms of epistemological production across many disciplines (bio-medicine, pharmacology, epidemiology, public health, community development, social sciences etc.) and involving many actors (the pharmaceutical industry, health systems, governments, civil society organisations, activists, educationalists, artists etc.). These deployments imbue moments of ‘discovery’ or ‘breakthrough’ with strong affective resonances: transforming a biomedical or epidemiological ‘fact’ into a revolutionary provocation to doubters or sceptics, and a global movement imbued with the power not only to end the epidemic but to transform the lives of individuals and groups in other ways.

Intimate knowledge

However, these political deployments of hope also carry with them the potential to invoke a false ontological promise inasmuch as they ‘flatten’ personal experience. In the U = U and Fast-Track registers, complex experiences of intimacy and embodied existence with and around HIV are constrained to manifest within a future-oriented temporal sphere which proclaims the liberatory potential of biomedical technologies. Thus, the complex and messy experiences of individuals are made invisible within discourses of hope, rendered illegible to historical or contemporary accounts.

In this paper, we re-visit people's accounts of their sexual and intimate lives in the context of HIV taken from qualitative research studies conducted between 1997 and 2016. Focussing on intimate and embodied experience (personal, social and sexual), we explore how twelve people encountered and came to know the HIV virus, various biomedical responses and their own infectiousness/vulnerability to infection. Our analysis employs Hugh Raffles' concept of *intimate knowledge*, described as:

...people enter[ing] into relationships among themselves and with nature through embodied practice; how it is through these relationships that they come to know nature and each other; and how the relationships, the knowledge, and the practice are always mediated not only by power and discourse, but by affect. [...] Affect, though inconstant, is also ubiquitous, the perpetual mediator of rationality.

(Raffles, 2002)

We follow Raffles in focussing on intimate forms of knowledge—embodied experience of self and nature—to amplify narrativised experience among people living with and impacted by HIV over the past 25 years. In doing so, we examine ways in which people create novel intimate spaces, understandings and knowledge which transform the intimate possibilities of their lives and in turn transform what HIV is—leading to the development of intimate and embodied enactments of ‘not inevitably infectious’, ‘more or less infectious’ and ‘uninfectious’.

METHODOLOGY AND SAMPLE¹

This research used secondary qualitative data analysis approaches (Corti, 2019; Hammersley, 2010; Heaton, 2004) to re-analyse 12 in-depth qualitative interviews conducted with people living with or around HIV at key points throughout ‘the biomedical era’ (see table below) to address the following questions (Table 1):

- At key points throughout the epidemic:
 - How did people living with or around HIV talk about their own infectiousness or vulnerability to infection and about questions of infectiousness more generally?
 - What impacts did infectiousness/vulnerability to infection have on peoples’ intimate, sexual and social lives and how did they manage/negotiate these impacts?

TABLE 1 Data sets and sample

Biomedical 'breakthrough moment'	Study data set	Respondent details
Effectiveness of ART is announced at Vancouver 1996 International AIDS Conference.	<p>Title: The impact of combination therapy on the lives of people with HIV</p> <p>Data collected: Summer/Autumn 1997</p> <p>Description: Experiences of people with HIV of starting and maintaining combination therapy. 40 In-depth interviews with diverse people with HIV.</p>	<p>40-year-old White British cis gay male. Diagnosed 1986. 'Robert'</p> <p>33-year-old Black African cis heterosexual female. Diagnosed in 1991. 'Lisa'</p> <p>29-year-old Black African cis heterosexual female. Diagnosed 1995</p>
'Swiss statement' on Treatment as Prevention is released January 2008	<p>Title: Relative Safety II</p> <p>Data collected: Winter 2007/2008</p> <p>Description: 42 in-depth interviews with gay men with diagnosed HIV focussing on accounts of sexual risk</p> <p>Title: Plus One</p> <p>Data collected: Winter 2010/2011</p> <p>Description: 60 in-depth interviews with people who had been or were currently in a relationship with someone of a different HIV status, and where at least one partner was Black African. Focussed on social, intimate and personal impacts of HIV</p>	<p>40-year-old white north American cis gay male. Diagnosed 1990 'Andrew'</p> <p>24-year-old white British cis gay male. Diagnosed 2007. 'Tim'</p> <p>41-year-old white British cis gay male. Diagnosed in 2006</p> <p>22-year-old Black African cis heterosexual female. Diagnosed in 2004. 'Angela'</p> <p>52-year-old Black African cis heterosexual female. Diagnosed in 2002</p> <p>35-year-old Black African cis heterosexual female. HIV negative/unknown</p>
PROUD Trial in UK shows high effectiveness with little 'risk compensation' for MSM September 2015	<p>Title: Being negative: gay men, sex, love and risk</p> <p>Data collected: Summer 2015</p> <p>23 interviews with men who knew or believed themselves to be HIV negative at the time of recruitment into the study and (b) had more than 12 sexual partners in the 12 months prior to interview</p>	<p>44-year-old white British cis gay male. HIV negative. 'Gareth'</p> <p>29-year-old white European cis gay male. HIV negative</p> <p>23-year-old white European cis gay male. HIV negative</p>

Sampling

We explored discourses on infectiousness at three moments of biomedical ‘breakthrough’ by selecting four data sets where fieldwork coincided with these moments. Three interviews from each data set were randomly selected to make up our sample of 12 respondents. The table above describes the ‘breakthrough moment’, the corresponding study data set/s and the three respondents selected from each data set.

Ethical issues

Ethical considerations attending this study are discussed elsewhere (Dodds et al., 2020); however, the main ethical issue to arise was questions of consent. In brief, the most recent data sets had data re-use in their original consent procedures whilst the oldest were collected prior to the normalisation of consent procedures for non-clinical studies. In collaboration with the UK data archive, we devised new ethical procedures for the preparation of qualitative data for re-use attending to three factors: consent, de-identification practices (anonymising) and access to data. These procedures specified a balance between these three factors, so that where one element is low, the others are strengthened. Thus, where original consent was absent or where re-use was not mentioned, de-identification practices were strengthened and greater restrictions on future access placed (including removing entire transcripts from data sets if necessary).

Analytic approach

One or both authors were involved with the original collection and analysis of these four data sets, so this is a re-encounter with once-familiar data. Our analytic approach differed from that adopted with the data originally which was thematic and deductive. For this analysis, we focussed on the case rather than the theme, attending to biographical aspects. Other than the specification of the topic (infectiousness), we used an inductive approach influenced by narrative analysis, letting the meanings and sense emerge from the experiences of individuals over time (Frank, 2013; Squire, 2013). Both authors read transcripts in detail, whilst the main analysis was conducted by the first author who was re-joined by the second author during interpretation of our findings. Although the findings we present here are based on an analysis of all twelve interviews, we have chosen to present findings through a detailed account of **six** of our twelve respondents in order to foreground a sense of biography and of time passing.

FINDINGS

1997: The treatments are working

Brief biographies of Robert and Lisa

‘Robert’ was a 40-year-old white UK-born gay man. He had been diagnosed 10 years previously in 1986 and for most of that time had experienced few to no symptoms. However, in the previous year, he had been mortally ill with tuberculosis. Since then, he felt that his health was compromised. ‘Lisa’ was 33 years old and had migrated to the UK from Uganda. She had been diagnosed 6 years previously in 1991. She had not experienced any serious illnesses.

Robert and Lisa's accounts were collected less than a year after the AIDS treatment 'breakthrough' moment at the Vancouver conference in 1996. Accounts of HIV in developed countries in the late 1990s tend to focus on a dramatic return to health for many who were near death. Writing in 2006, Howard Grossman, then the Executive Director of the American Academy of HIV Medicine writes.

[...] The effect was so profound that it's hard, even now, to judge. In my practice alone, there were 37 deaths in 1995. In 1996, the number of deaths fell to 10, in 1997 to 4, and in 1998 to zero. HAART [Highly Active Antiretroviral Treatments] caused what is often described as the 'Lazarus effect'. People like my patient, John, who thought his life was coming to an end, were rapidly becoming healthier.

(Grossman, 2006)

Biomedical accounts of this period were marked by a certainty that, for the present at least, new HIV treatments were 'working': they were delivering decreases in viral load and a diminution of morbidity in those who could access them.

However, in intimate embodied accounts, the question of 'working' was more complex. After witnessing serious adverse reactions to previous anti-HIV drugs, and in particular AZT, Robert, like many others was ambivalent about starting on the new drugs (Anderson & Weatherburn, 1998). He eventually commenced the treatments, and shortly thereafter, his physicians deemed his response to be sub-optimal and wanted to change his regime.

My [viral load count] had dropped significantly. I had a feeling that it might have, because I was feeling well, so I was kind of: 'yeah it is getting a bit better', and I was right. Er and they [doctors] were thrilled because [viral load] had gone from something like 150,000 or 170,000 and they eventually got it down by July to thirty-five. They were pleased with that. [...] What I hadn't realised until I was at the 175,000 mark, whenever that was, maybe May, was that it had been six and half million [...]. So of course when he said that to me, I said 'well, it was six and half million – I think something's working here'. 'Yes, but not enough' [says doctor]. I said 'well I'm quite happy, thanks very much'.

Robert goes on to say:

[The doctor] just said to me 'I'm taking you off them', not that he wasn't terrified at having to tell [me]. It's a major thing for a doctor to have to tell you, knowing that there aren't really that many other options. So he did it very kind of briskly, you know, said 'that's it', and I said 'oh dear, that's not very good' and tried to laugh it off, and I said 'you know it took me ten years to pluck up the courage to put an AZT tablet in my mouth', I said 'it's taken ten months for it to prove not to work, and ten minutes just to throw it in the bin'.

Robert's account lends a disorienting aspect to the ways in which treatments 'working' is experienced. Regardless of his physical or mental state, or his own interpretation of clinical indicators, his treatments are deemed by his clinician not to work. New treatments thus heralded a world of new uncertainty; where death is no longer certain, but then neither is life (nor what 'life' might entail); where powerful, but seemingly perverse logics prevail; where not being well enough is sufficient to render a 'miracle treatment' as having 'failed'.

Lisa's engagement with biomedical responses to HIV also predated the breakthrough of 1996. Her account of her first pregnancy gives us an insight into how infectiousness was perceived and managed. At the time of her diagnosis in 1991, Lisa was in a relationship and had been trying to conceive. When she received an HIV diagnosis, both she and her partner assumed that he must also be infected but he did not want to test. Shortly after this, Lisa found she was pregnant. She was receiving her HIV care from a central London clinic.

The hospital was totally against my having a child. They were like, 'That child will be orphaned. That child will soon be HIV, could be HIV positive'. And for about five months the HIV consultant kept on asking me whether to have a termination, really pushing for a termination to the extent that I decided I would change [my doctor] within the same hospital. And I tried and one of [the] senior consultants within the clinic actually came to talk to me. [...] He asked me why I was changing [my doctor] and he told me the difficulty was the other doctors won't finish it [agree to treat Lisa through her pregnancy]. They'll think the problem is with me and I would find it extremely hard to get another doctor if I decide to leave that doctor. And that scared me so I changed hospital and I moved to [another central London hospital] a well-informed hospital. And the doctors there were totally different, the midwives were different. They were so caring. The treatment I received in the two hospitals was just completely different and moving to [name] in a way made me enjoy the last stages of my pregnancy...

Lisa was perceived as irretrievably infectious: as she is infected, then so must her partner be and so inevitably will her child. However, Lisa resisted this characterisation, changed hospitals and eventually delivered her child without transmission. Around the time of the birth of her child, her partner finally tested, and surprisingly for both, tested HIV negative.

Through conceiving and giving birth without infecting either her partner or her child, Lisa created for herself an intimate space where she is not inevitably infectious, where she is differentially or 'more or less' infectious. After finding he was not infected, her partner ended the relationship. Lisa started a relationship with another (HIV positive) man with whom she had a second child—who was also delivered without HIV transmission occurring.

These accounts alert us to the possibility of multiple meanings at play when considering what it means for treatments to 'work' or that they are 'working': meanings not legible either in contemporary or historical hope-laden biomedical or political accounts. What 'working' meant was a contested point both for Robert and Lisa. For Robert, his prognosis bore little relationship to how he felt in himself: to his embodied experience. In Lisa's case, she had to break with those treating and monitoring her to eventuate the possibility of delivering an uninfected child.

Neither Robert nor Lisa's experiences entailed the Lazarus type recovery that predominate accounts of the mid to late 1990s. Rather they describe the continuation of the painfully uncertain and open-ended negotiations that started when they were diagnosed: engagements necessitated by the struggle to live, or keep living, with HIV. This daily struggle forms a key part of treatments 'working', as also recounted by Squire (2013). Moreover, the achievement of both 'normal life expectancy' and the promise of being non-infectious that the taking of HIV treatments now generally entails have actually required multiple further engagements over the next twenty or so years: the unregistered embodied and intimate work of people living with or around the virus.

2008–2010: being infectious

Brief biographies of Andrew, Tim and Angela

‘Andrew’ was a 44-year-old North American gay man, diagnosed in 1990. At the time of interview, Andrew had not experienced any HIV-related symptoms or ill health, but had suffered multiple HIV-related bereavements. The decade after 1996, was for Andrew a time of sexual exploration involving many sexual partners on the commercial gay scene both in the UK and USA.

‘Tim’ was a 24-year-old British gay man who had been diagnosed with HIV in the year prior to interview. Like Andrew, Tim had been and remained highly sexually active on the London commercial gay scene. Prior to and after his diagnosis, Tim inhabited a social and sexual milieu that included both HIV positive and HIV negative people.

‘Angela’ was 22 at the time of interview. She had moved to the UK from Uganda 5 years previously and had been diagnosed soon after this. Three years previously, she gave birth to a child whom she had with her current male partner who tested HIV negative at the time she became pregnant.

The decade following the introduction of highly effective treatments in 1996 saw reductions in mortality and morbidity accompanied by steady levels of new infections. By 2008 in the UK, there was a substantial and growing population of people living with HIV, on treatments and virally suppressed (Health Protection Agency, 2008). Although HIV prevention had always been a priority, concerns about this healthy, sexually active HIV-positive population as a source of infection grew. Many states around the world adopted practices of prosecuting and incarcerating those deemed to have knowingly or recklessly risked infecting sexual partners or others with HIV (Cameron & Reynolds, 2010; Dodds et al., 2005).

As an intervention to protect people with HIV from prosecution, in January 2008, the Swiss National AIDS Commission issued a statement by doctors in Switzerland about the safety of HIV treatment to control transmission (Vernazza et al., 2008). The ‘Swiss statement’ asserted that, with some caveats, an HIV-positive person on effective HIV treatment and consistently virally suppressed cannot transmit HIV through (hetero) sexual contact. The Swiss statement achieved global purchase precisely because many clinicians, epidemiologists, community activists and people living with or around HIV already suspected this to be the case. Thus, the Swiss statement can be seen, in hindsight, both as a provocation and the formulation of a hypothesis to be tested in large scale population trials. Two of the three accounts covered in this section, Andrew and Tim, were gathered as the Swiss statement was being launched, whilst the third, Angela, was collected about 2 years later. They give us some insights into the meanings and experiences of infectiousness in circulation at this time.

Andrew was first celibate and then in a monogamous relationship following his diagnosis in 1990. However, in 1996, Andrew’s relationship ended and he talks about becoming sexually adventurous visiting bathhouses and engaging in the fetish and S/M scene.

The question of being infectious emerged strongly in Andrew’s accounts of this period. He was not on treatments and remained asymptomatic with normal CD4 counts and an undetectable viral load, defining himself as a ‘slow- or non-progressor’. Here, he describes engaging in unprotected sex with anonymous or casual partners.

I really felt guilty [about non-condom use] sometimes but then I, I had like a zero viral load with no medication until around 2003 – 2004 [...] So it was a situation of long term non-progression so I justified it, I did for a time I justified it to myself by saying ‘yeah well you are not likely to be very infectious’.

Andrew's embodied sense of himself as ‘not likely to be very infectious’ has strong affective and moral dimensions: he feels guilt at the prospect of infecting someone. He developed personal strategies around disclosure to different partners, resulting in a kind of intimate work around his infectiousness and other people's responses to it.

[...]if you were just meeting someone on a one time basis, and us[ing] a condom then it doesn't really matter. But there were other occasions, there was another occasion, a couple of occasions, where I had sex with someone but kept seeing them but hadn't told them I was HIV and basically stopped the relationship because um, because it became impossible to say that. So, I thought it was just easier to be out with it from the beginning. [...] And also I kind of preferred having sex with other people who were HIV positive and that was the only way you can do that is by being open about it.

[W]as it always a case that you were more comfortable having sex with guys who were HIV positive or did that come later on?

[...] I always had some moral qualms [about not disclosing] and eventually I just decided that complete disclosure was the easiest way to do it. ...and then people began not wanting to use condoms, you know, I um, and I would get very mad I would keep up this condom code and then I just thought oh no...

Ok so you felt there was a point perhaps where people stopped dying from HIV and AIDS?

...or gay men, amongst the groups of people I knew, stopped dying.

Andrew's accounts of his sexual and social life post-1996 gives us a glimpse into a period where HIV was in the process of ‘normalisation’ necessitated, in part, by the presence of people with HIV who were relatively healthy and sexually active (Squire, 2013). This process consisted in the working out of new social, moral, affective and intimate norms, new ways of organising intimate lives and new knowledge around sexual HIV risk within certain sexual and social networks of gay men (Adam, 2005; Halkitis, 2010; Keogh, 2008).

Though 20 years Andrew's junior, and diagnosed only 6 months prior to interview, Tim echoes Andrew's account of needing to work through the moral and affective consequences of his own infectiousness in relation to future intimacies. In the following quote, Tim is discussing a relationship he had in the early 2000's before he was diagnosed with a partner who was HIV positive.

He was positive and um his viral load was undetectable at the time. And um we discussed uh unprotected sex. But I wasn't ready for it and he wanted um me to fuck him and cum in him, but I wasn't ready for that.

Ready in what way? What do you mean?

Um. I think there was a few factors. I think we'd only been together for about four or five months and um basically I wasn't in love with him. And uh I think you know if I had have been it might have been different. [...] I just didn't want to put myself at risk. [...] I think probably people in um those kinds of relationships where you've got one positive partner and one negative. I think that [sex without condoms] would probably occur. [...] It would definitely be discussed. It would just be more intimate as well.

Tim has a sense of infectiousness mediated by whether one is 'undetectable', a perception which is influenced heavily by the affective context of the encounter. Had he loved this partner, Tim may have taken the risk of infection on the understanding that his partner's infectiousness is not virulent, and the consequences of infection can be managed through treatment.

Tim and Andrew share complex understandings around infectiousness which are profoundly embodied, personalised and contingent. Infectiousness is understood and ultimately managed through intimate and embodied enactments where love, desire, guilt and risk are all held in the balance. Crucially, it is this intimate work that enables the guilt, love, desire and risk that accompany uncertainty around infectiousness to be managed within intimate relationships.

Angela's account contrasts markedly with Tim's and Robert's and illustrates how the nature of intimate work and enactments around infectiousness are influenced by material and structural factors such as gender. Angela shared the same moral and affective meanings and functions around infectiousness as Tim and Robert, and she disclosed her HIV status to her HIV-negative partner at the outset of the relationship. For Angela and her partner, the intimate possibilities of their relationship encompassed concerns about their reproductive capacity as a couple.

... he was like 'oh can you still have your P's? [periods]. Can you have babies if you have HIV and things like that, which I didn't know whether I could or not but. I knew because there is nothing wrong with me to have babies but with the situation I didn't know what is going to happen when it comes to having children you know.

Her partner wanted to know whether HIV may have rendered Angela infertile, whereas Angela was more concerned about how to conceive and give birth without the risk of infection.

Unlike Tim and Robert, Angela was very uncomfortable with the possibility of non-condom use. Angela experienced herself as infectious despite having a suppressed viral load. Hence, she would only have sex with her partner using a condom and used a self-insemination technique to conceive. Angela and her partner bore an intimate burden around infectiousness which coloured their entire relationship.

But being negative it got to the point that he couldn't take it anymore but when it comes to being together you have to use rubbers all of the time and that is when he got fed up. [...] As far as other things are concerned, normal life everything remains normal, but when it comes to sleeping together that is when the problem comes and you know when someone is not happy, when he is not happy in the bedroom every small issue becomes a big issue.

Andrew, Tim and Angela were clearly 'feeling their way around' intimacy, sex, risk and infectiousness through tentative engagements with biomedical interventions such as HIV treatments or biomedical forms of knowledge such as viral load. However, the intimate work of crafting ways of living, loving and having

sex in an epidemic transform not only how HIV is experienced but also the meanings attached to being infected, being infectious and becoming infected with HIV.

Moreover, we can see how understandings of the relationship between viral detectability and infectiousness were in circulation amongst people living with and around HIV many years before the 'breakthrough moment' of the Swiss statement. What is most significant about these findings, however, is the intimate work entailed in developing and maintaining these understandings by creating hitherto unimaginable intimate spaces within which infectiousness could be managed.

We can see therefore, how intimate engagements bring into being an emergent and embodied knowledge that infectiousness can frequently be managed, is not inevitable, and that people can have condomless sex without infection. This knowledge opens up a social and political space within which provocations such as the Swiss statement become feasible.

2015: 'Uninfectious'

Brief biography of Gareth

Gareth was a 44 year old white British HIV negative gay man. He had socialised on the London gay scene since he was 19 and his social circle had always included many close friends and acquaintances who were HIV positive.

Gareth had engaged regularly in recreational 'club' drug use in the past, but not so much in recent years.

Although the effectiveness of HIV pre-exposure prophylaxes (PrEP) had already been demonstrated by 2011 (Grant et al., 2010), a milestone in the UK PrEP story was the publication of the results of the PROUD trial in January 2016 (McCormack et al., 2016). PROUD (re) confirmed PrEP effectiveness but also inaugurated a highly public ongoing struggle between UK government and advocates to make PrEP available on the NHS. A BBC documentary about this struggle quotes Sheena McCormack, the lead scientist in the PROUD study as saying: 'We probably had done as much as we possibly could in the way of frequent testing, early diagnosis and early treatment. The piece that was missing was the HIV-negative individuals who were catching HIV in-between their HIV tests. That's where PrEP fills the gap' (Castella, 2018).

Gareth's account tells us much about how such HIV-negative gay men accommodated the virus in their social intimate and sexual lives at this time and how these accommodations could bring about transformations not only in terms of their understandings of HIV, but also to the way in which they enact their intimate and sexual lives. In particular, we see how the concept of being 'uninfectious' gained meaning for Gareth through his lived experiences.

Gareth describes his twenties as a period where he avoided sex with men he knew to be HIV positive and consistently used condoms. However, as he moved through his thirties, his fears around infectiousness gradually lessened. Remembering his early thirties, he recalls occasionally engaging in condomless sex whilst his was high and being more or less worried about these instances. He stresses the importance of knowing the partners with whom he occasionally engaged in condomless sex. However, 'knowing' for Gareth encompassed more than the likely or actual HIV status of his partner, it was associated more with whether his partner might be vulnerable to infection or indeed infectious. This understanding of vulnerability to infectiousness emerged through Gareth's use of recreational drugs during sex. The following account of condomless sex was one that prompted Gareth to seek an HIV test shortly after it occurred.

I do remember one specific time, when I had bareback sex with someone I'd known for a long time, and he's still negative now, as far as I know, but we did have quite... I don't want to say risky sex, but just bareback sex is risky anyway, but he used to get really, really off his face on GHB, and without really knowing it, he gets a little bit violent, but not intentionally violent. He's just one of those people that used to flail his arms everywhere, and I remember there was a bit of blood. I don't know if it was just from me, or from him, after he fucked me.

Gareth explains his concerns in terms of the interaction between recreational drugs use and immune functioning. When asked why he was worried in this instance, Gareth says:

... sex on drugs, it lasts for a long time, and that's when you're prone to get cuts and all sorts of other things. And you're probably more likely – because your immune system's been battered by the drugs you've taken – to be a lot more battered, so you're more likely to get...

You're more vulnerable?

Exactly. Whereas I know, if you have bareback sex and you're completely sober, no drugs inside you, you know the person's a healthy person, then it won't last as long, it'll probably last on average half an hour. So you're not battering each other!

Battering each other?

I mean your, kind of like, immune system [...] I know it sounds ironic, but I find bareback sex with someone that's not on drugs a lot more desirable, and probably safer, than with someone that's off their face on drugs.

Various understandings around sexual risk are condensed in this quote. Sex whilst not on drugs is likely to be gentler and for a shorter duration and will therefore involve less possible trauma and hence exposure. However, sex whilst not on drugs is also healthier, in terms of immune functioning. Drugs compromise immune functioning thus making a non-infected partner more open to infection and an infected partner more infectious.

This embodied, barely enunciated knowledge is what allowed Gareth to feel comfortable engaging in condomless sex. Like Lisa, Gareth had created an intimate space in which condomless sex is imaginable and possible and infection was not inevitable. Thus, by the time of his interview, condomless or 'bareback' sex with different partners had become not only imaginable or possible but an everyday part of his sexual and intimate life.

DISCUSSION

Our re-analysis describes a form of embodied accretive knowledge borne of affective, intimate and moral imperatives. Infectiousness—and uninfectedness—takes meaning in response to the challenge of living with or around HIV. Responses crafted by those faced with this challenge make imaginable and hence bring into being ways of living with the virus, of living with the risk of infecting

another or of being infected. Thus, ideas once unthinkable—planning a future, having a baby, engaging in condomless sex and being uninfected become first thinkable, then practicable.

For all their merits, technologies of hope such as U = U and Fast-Track enact a mis-recognition of this embodied, textured knowledge, abstracting the lived experience of being uninfected into an epidemiological or socio-legal certainty tied to adherence to a pharmaceutical regime. This casts us into an historical false consciousness regarding how we managed HIV prior to the era of pharmaceutical certainty and renders the types of knowledge that sustained us through these periods redundant.

Technologies such as U = U are themselves dependent on precarious political and economic conditions. It is fallacious to disregard the way in which such technologies and their attendant HIV identities fare in environments with frequent treatment stock-outs, where HIV remains stigmatised, and where personal precarity makes treatment adherence impossible. The history of the biomedical era has been characterised, with some justification, as a cycle where breakthrough is followed by disappointment (Borup et al., 2006) and already uncertainty is growing around the kinds of technical assemblages (such as U = U) that are supposed to deliver an end to HIV transmissions globally by 2030 (Braithwaite, 2018; Cousins, 2016; Kelly et al., 2018). A return to the kinds of knowledge we describe in this paper may be helpful therefore. These are knowledge whose strength lie in their capacity to weather contingency and precarity precisely because they are not expressed within a logic of hope or expectation, but rather because they are borne of the need to live with a condition as best one can. Attending to intimate knowledge may enable us to temper the unrealistic claims of biomedicine as well as our understandable hopes for eradicating HIV.

More broadly, we propose the concept of *Intimate Knowledge* as having two potential uses in sociological research on health and illness.

We propose it first as a critical tool. The power of hope-laden, future-oriented biomedical, knowledge assemblages lies in their claim to universality and infallibility; to validity regardless of context. Moreover, like much innovation in health and healthcare systems (Gabe et al., 2015), they are ultra-legible to marketised health systems. They promise to reward investment in lives saved, profits made, health systems supported and communities empowered. They also serve, of course, to support pre-existing power structures and neoliberal rationales of progress. However, in their claim to universality, they cast the embodied knowledge described in this paper as local, specific, contingent and destined to remain peripheral and parochial (Clarke et al., 2010).

The intimate accounts we describe stand out because they are not readily available to appropriation within discourses of hope. This allows us to (re)connect embodied and intimate spheres to political and social ones in ways that temper the ‘hopefulness’ of such technologies thus enabling us to ‘critically question [...] the values incorporated within the social representation of hope as a positive attribute of health or as the goal of medicine’ (Petersen & Wilkinson, 2015:114). Thus, intimate accounts trouble a presumed consensus around the spectacular potential of biomedical technologies. They also offer the possibility of creating less partial and more nuanced accounts of biomedical transformations by enriching them with embodied and affective experience.

Second, we propose intimate knowledge as a bridging concept between bifurcated traditions in social research in health and illness. Critical theoretical work focusses on social and political processes around illness and health, on bio-communities and bio-identities, on the production and consumption of different forms of bio-capital and governmental and economic imperatives. In contrast, psychosocially oriented research focusses on embodied experience and on the intimate and social arrangements around illness and health.

Raffles’ framing of *Intimate Knowledge* is helpful because it emphasises the centrality of situated knowledge borne of experience and encounter and ‘fundamentally tied to contingency and habitus’ (2002:236) as an essential mediator of the forms of rationalities espoused in scientific or

epidemiological forms of knowledge production. Thus, *Intimate Knowledge* as a working concept makes space for intimate, embodied experience of health and illness within critical epistemological registers whilst enhancing the critical potential of work undertaken in psychosocial traditions.

AUTHOR CONTRIBUTION

Peter Keogh: Formal analysis (lead); funding acquisition (supporting); investigation (equal); methodology (equal); project administration (equal); writing – original draft (lead); writing – review and editing (lead). **Catherine Dodds:** Formal analysis (supporting); funding acquisition (lead); investigation (equal); methodology (equal); writing – original draft (supporting); writing – review and editing (supporting).

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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ENDNOTE

- ¹ This research was conducted as part of a Wellcome Trust funded study (1104522/Z/15/Z) which aimed to prepare 12 qualitative data sets collected between 1997 and 2016 for inclusion in the ESRC data archive and to conduct an initial re-analysis across them. These data sets contain accounts of the intimate lives of 612 people collected at different points in the UK HIV epidemic (names removed for review). A methodological paper on this study has been published elsewhere (Dodds et al., 2020).

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